

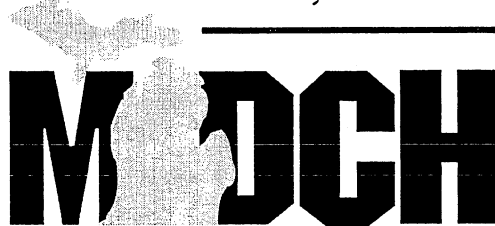
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# **Statewide Quality of Life And Service Satisfaction Study For Children and Families**

Division of Quality Management and Planning  
Quality Management and Customer Services Administration

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*Michigan Department  
of Community Health*



John Engler, Governor  
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The Department of Community Health (DCH) is required to submit an annual report on its community mental health services programs (CMHSPs) to members of the house and senate committees on community health, the house and senate fiscal agencies, and the Department of Management and Budget. Section 407 of the DCH Appropriations boilerplate mandates that information on the quality of life of public mental health service recipients be contained in the report. In Spring 2001, the department conducted its first statewide study of the quality of life of children and families served through the community mental health system. This study also assessed their satisfaction with services. Children and their families who receive mental health services or services for persons with developmental disabilities (DD) were included in this study. The study provides a multi-dimensional assessment of the quality of life of children and their families and an assessment of their satisfaction with services.

There are many definitions of quality of life. In this study, quality of life was defined as:

An overall general well-being that is comprised of objective and subjective evaluations of physical, material, social, and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values.

This study used psychological indicators of quality of life to reflect the individual's life experiences and personal satisfaction with his or her life. Other approaches were considered including the use of social indicators based on environmental conditions (e.g., health, social welfare, friendships, standard of living, education, public safety, housing, neighborhood, leisure activities) or goodness-of-fit indicators, which assess the congruence between environmental demands and a person's control of resources and skills to meet these demands. The use of psychological indicators was considered to be the best match with the purposes of mental health services.

Quality of life for children was defined in terms of seven domains: home life, school life, community participation, relationships, personal development, choice/self-determination, and overall quality of life. The instrument that was selected was able to address satisfaction with five of the seven domains: family/home life, school life, community environment, social relationships with peers. The literature on family quality of life is limited but was explored in-depth during the design of the study. Quality of life for parents was defined as the degree to which resources received from other family members satisfied personal needs for love and affection, respect and esteem, comfort

and assistance, shared meaning, personal possessions, and money for personal use. These were the domains covered by the selected instrument.

An advisory group to the project met for a year to define quality of life, select appropriate instruments, and design the study procedures. The group consisted of nine representatives from CMHSPs, five advocacy organizations, and five DCH staff (four from Mental Health Services to Children and Families and one from the Division of Quality Management and Planning). Representatives from advocacy organizations included two parents and a person with a developmental disability.

## Procedures

### Eligibility criteria

Children and their families were identified as eligible for the study if the child met three criteria. First, the child's age was less than age 18 as of September 30, 2000. Second, the child was living in the community with family or in foster care. This meant that the child was not living in a DD Center, a psychiatric hospital (state or community), a residential care facility, or nursing home. Third, the child and/or family received services from a CMHSP between October 1, 1999 and September 30, 2000.

### Sample selection

A random sampling procedure was used that gave every child in four categories, who met the study eligibility requirements, the same probability of being selected for the study. Four samples were selected: (1) children ages birth to six with DD (N = 100); (2) children age birth to six served in mental health services for children (MIC) (N = 200); (3) children ages seven to 17 with DD (N = 100); (4) children age seven to 17 served in MIC (N = 400). Sample sizes were set to provide samples large enough to detect reasonable differences in quality of life and service satisfaction and to allow for a 50 percent refusal rate.

### Interview process

Each CMHSP was requested to identify a liaison for the study. This person's responsibilities included obtaining the initial list of identification numbers for eligible children, contacting selected families, and coordinating the interview process at their CMHSP. A letter to parents about the study was provided to the CMHSPs. The letter explained the purpose of the study and what would be involved in participating; emphasized voluntary participation; and indicated that parent and child participants would be paid \$25. Informed consent was obtained from each participant at the time of the interview. Participants could initially agree to participate and decline later. CMHSP liaisons also called selected families to determine their interest in participating. CMHSP liaisons and interviewers set up the interviews.

### Interviewer training

Interviewers were identified by CMHSPs. Interviewers were CMHSP staff that had no previous or current relationship with the consumer. The Association for Children's Mental Health and the ARC-Michigan also were asked to identify potential parent interviewers. Eleven parent interviewers were identified. DCH staff trained the interviewers. Several parents participated in the training and one served as a trainer for additional parent interviewers. Five hours of training were provided live in Lansing and via television in Marquette, Sault Ste. Marie, Harrison, Muskegon, University Center, and two sites in Wayne County. Training materials were provided to each interviewer and included the interview forms, background data forms, general instructions, and copies of training slides. The interview forms were presented and how to administer each section and question were reviewed. A question and answer period was part of the training.

### Background data on selected children

Background data was obtained from the CMHSPs on each consumer selected for the study. The items requested were the same as the Consumer Demographic Data found in the required contract reporting of the MDCH/CMHSP Managed Specialty Supports and Services Contract. These included demographics, living arrangement, employment status, income, and diagnosis. For children with mental health issues, CAFAS scores were requested. For children with developmental disabilities, information was requested on level of mental retardation, communication style, mobility assistance, medication administration, personal assistance, household assistance, community assistance, health status, and behavioral challenges. Information was requested on the type and amount of services used between October 1, 1999 and September 30, 2000.

### Who was interviewed

The child as the consumer was interviewed about his or her quality of life and satisfaction with services for children ages seven to 17. Parents were interviewed for all age children regarding their perceptions of their children's quality of life. Only parents were interviewed for children ages birth to six.

### The interviews 1

The child interview included the Multi-dimensional Student Life Satisfaction Scale (MSLSS; Huebner, 1994) and the Youth Satisfaction Questionnaire on services (Center for Mental Health Services). The same instruments were used for both children with mental health issues and children with developmental disabilities. For children with mental health issues, the MSLSS was scored on a six-point scale ranging from strongly disagree (1) to strongly agree (6). For children with developmental disabilities, the MSLSS was scored on a four-point scale ranging from never (1) to almost always

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1 Instruments are available from the Dept. of Community Health upon request.

(4). The use of different scales was based on advice from the author of the scale.

The parents interview contained a parallel parent scale based on MSLSS and was scored on a six-point scale ranging from strongly disagree (1) to strongly agree (6). The parents interview was not a surrogate interview but focused on the parents' perceptions of their children's quality of life. The parents interview also included Feelings About Family (Rettig, 1999); Family Empowerment Scale (Koren, DeChillo & Friesen, 1992) and the Family Satisfaction Questionnaire on services (Center for Mental Health Services).

The MSLSS has five scales: family, friends, self, school, and living environment. Higher scores on each scale indicated greater satisfaction with this life area. The mean score on each scale provides a subjective assessment by the child of this area of his or her life.

The Youth Satisfaction Questionnaire and Family Satisfaction Questionnaire have seven questions. The first question asks about overall satisfaction and the other six questions ask about specific aspects of services. The questions were answered on a five-point scale ranging from (1) very dissatisfied to (5) very satisfied.

The Feelings About Family scale has six subscales: love, status, services, information, goods, and money. Love is defined as expression of positive regard, warmth or comfort. Status is defined as another's evaluative judgments of the person's prestige, respect, or esteem. Services are defined as concrete activities provided by one person to another to increase the comfort of another. Information is defined as providing advice, opinions or instructions. Goods are defined as tangible objects or materials provided for the person. Money is defined as the amount available to the person. Items are scored on a seven-point scale where (1) is terrible and (7) is delighted.

The Family Empowerment Scale has three subscales: family, service system, and community/political. The family subscale assesses the parent's feelings of empowerment with regard to their family life and child. The service system subscale assesses the parent's feelings of empowerment with regard to services the family and child receive. The community/political subscale assesses the parent's feelings of general empowerment when dealing with government. The questions were answered on a five-point scale ranging from (1) not at all true to (5) very true.

## Results

### Participants

The final selected sample numbered 801. Of these families, 18.7 percent were interviewed. The other 81.3 percent refused (13.0 percent), could not be located (25.5 percent), or the reason for non-participation was not reported (42.8 percent). By subgroup, 14.0 percent of parents of children ages seven to 17 receiving MIC participated; 10.5 percent of parents of children ages birth to six receiving MIC participated; 37.0 percent of parents of children ages seven to 17 receiving services for persons with DD participated; and 36.0 percent of parents of children ages birth to six receiving services for persons with DD participated. Among the children, 56 (14.0 percent) in MIC programs and 13 (13.0 percent) in DD programs participated.

Characteristics of the children. Tables 1 to 3 present the demographic characteristics of the children and the services they received. Both groups of children were young teenagers. The MIC group had nearly equal numbers of males and female. The DD group was three-quarters male. Both groups had a majority of white respondents. In the MIC group, attention deficit hyperactivity disorder was the most frequent diagnosis. In the DD group, mild mental retardation was the most often reported diagnosis.

Services received. In the MIC group, over half the children had received mental health therapy and assessment services. Slightly more than 40 percent of this group had participated in person-centered planning. In the DD group, 69 percent had received respite and 46 percent had received assessment services. Slightly more than two-thirds of this group had participated in person-centered planning and received services coordination.

Characteristics of parents. The majority of parent respondents were female (92.7 percent) and the mother of the child (83.3 percent). The majority of respondents were between the ages of 31 and 55 (75.2 percent). Almost all lived with their child (97.3 percent).

### Quality of life for children

The children's ratings of their satisfaction in the five life areas are presented in Table 4. Their parents' ratings of their satisfaction with the child's life areas are also presented. For children with DD, the scales are scored on a four-point as opposed to a six-point scale and their scores cannot be directly compared to their parents' scores. In general, children in MIC and DD groups indicated they were satisfied with all life areas. Their parents similarly were satisfied with all life areas.



### Satisfaction with services for children and parents

Children's and parents' ratings of their satisfaction with services are presented in Table 5. In general, both children and parents were satisfied with their services. Children with MIC gave a somewhat lower rating to the various aspects of their services than did their parents. These results should be used with caution because of the small number of respondents.

### Quality of life for parents

Parents' ratings of their family quality of life are presented in Table 6. There are no differences in the level of satisfaction with family life between parents with children in different age groups or in different disability groups. Although there is some variation in the ratings of various components of family life, there are no significant differences. In general, parents were mostly satisfied (rating of 5) with the various components of family quality of life. Money was the one area where ratings indicated parents had lower satisfaction (rating 4, mixed satisfaction).

### Family empowerment

Parents' ratings of their feelings of empowerment are presented in Table 7. There are no differences in the level of empowerment between parents with children in different ages groups or in different disability groups. Parents did feel more empowered in terms of dealing with the service system than they did within their own family or in the general community/political area. This suggests that parents in this study believed that they are listened to and involved in the treatment of their children.

### Summary

Few families were willing to participate in this study. The results of the study cannot be used to make general statements about the quality of life for children who receive mental health services or the quality of life of their families. The limited participation of parents and children also limits the extent to which the service satisfaction information can be generalized to the mental health system as a whole. Families who participated may have been more satisfied or had greater involvement with the service system than families who chose not to participate or who could not be located.

The study does demonstrate that it is possible to obtain quality of life and service satisfaction information from children and families. The methods used to identify families for, and to engage them in, such studies needs to be changed. In this study children were identified as eligible if they had received any services any time during a one-year period. This selection window appears to be too broad to permit identification of children and families with recent experience with mental health services. A shorter time interval, such as the most recent quarter to the start of the interviews, might

provide a pool of families who are still engaged with the mental health system and willing to be interviewed regarding their services and quality of life. The amount of contact with the mental health system was problematic in this study. CMHSPs reported that many children selected for interviews had little or no contact with the CMHSP after their case was opened. Families' willingness to participate might be increased by selecting from children who have at least two service contacts during the three-month selection window. These two changes in identifying eligible children and families would limit respondents to only those who are actively receiving services at the time of the study.

Children with Serious Emotional Disorder (SED) were able to complete the interview form with few problems. Children with DD were less able to complete the interview. As with adults with DD, the demands of the instruments pose great challenges for children with cognitive disabilities. Verbal interviews cannot be used with all eligible children with DD. Other methods for assessing quality of life will need to be identified if children with the most severe cognitive disabilities are to be successfully included in the process. As with this study, proxy responses should not be used. Examples of alternatives to verbal interviews include observational checklists completed by trained observers and application of a set of objective standards for minimal quality of life. These alternative methods may involve more cost than the use of an interview.

## References

Huebner, E.S.(1994). Preliminary development and validation of a multi-dimension life satisfaction scale for children. *Psychological Assessment*, 6, 149-158.

Rettig, K. (1999). Feelings About Family: A general theory for perceptual indicators of family quality of life. *Social Indicators Research*, 47, 307-342.

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Table 1. Characteristics of children with mental illness (MIC)

	Number	Percent
Gender		
Male	28	50.0
Female	26	48.1
Not reported	2	3.6
Ethnicity		
Native American	2	3.6
African American/Black	2	3.6
White	46	82.1
Multi-ethnic	2	3.6
Not reported	2	3.6
Primary diagnosis		
Adjustment Disorder	10	17.9
Attention Deficit Hyperactivity Disorder	21	37.5
Major Depression/Bipolar Disorders	10	17.8
Other	6	10.7
Not reported	9	16.1
Services received		
Mental health therapy and counseling	34	60.7
Assessment and evaluation	31	55.4
Person-centered planning	23	41.1
Supports and service coordination	15	26.8
Respite care	15	26.8
Medication administration	13	23.2
Home-based services	9	16.1
Family skills	6	10.7
Wrap-around	4	7.1

Table 2. Characteristics of children with developmental disabilities (DD)

	Number	Percent
Gender		
Male	10	76.9
Female	3	23.1
Ethnicity		
African American/Black	3	23.1
White	8	64.5
Arab American	2	15.4
Primary diagnosis		
Autism	3	23.1
Mild mental retardation	5	38.5
Moderate mental retardation	2	15.4
Severe mental retardation	1	7.7
Not reported	2	15.4
Services received		
Respite care	9	69.2
Assessment and evaluation	6	46.2
Person-centered planning	5	38.5
Supports and service coordination	5	38.5
Mental health therapy and counseling	4	30.8
Medication administration	3	23.1
Home-based services	2	15.4
Family skills	2	15.4
Emergency services	2	15.4
Assistance with challenging behaviors	2	15.4

Table 3. Ages of children

	Children with MIC	Children with DD
Mean	12.46	13.15
Range	4-19	5-18
Standard deviation	4.12	4.27

Table 4. Children's quality of life

Children with MIC				
	Child Perception		Parent Perception	
	Mean	SD	Mean	SD
Family	4.47	1.23	4.74	0.72
Friends	4.83	1.01	3.89	1.32
Self	4.97	0.72	4.83	0.73
School	4.36	1.11	3.91	1.26
Living environment	4.20	1.12	4.12	1.12
Children with DD				
	Child* Perception		Parent Perception	
	Mean	SD	Mean	SD
Family	3.40	0.68	5.18	0.57
Friends	3.19	0.81	4.81	.088
Self	3.29	0.80	5.33	0.33
School	3.23	0.68	5.20	0.61
Living environment	3.40	0.85	5.05	0.75

\* For children with DD, the scales range from (1) never to (4) almost always. Scales for parents of children with DD, and parents and children with MIC range from (1), strongly disagree to (6), strongly agree.

Table 5. Satisfaction with services

	Children with MIC			
	Child (n = 54)		Parent (n = 76)	
	Mean	SD	Mean	SD
Satisfaction with				
Overall satisfaction	3.91	.98	4.21	.96
Providers' respect for family beliefs about mental illness	4.10	1.16	4.36	.85
Providers' understanding of family's culture	3.80	1.04	4.32	.83
Providers' ability to find services based on family strengths	3.57	1.21	4.12	.91
Level of involvement in planning	3.78	1.09	4.35	.88
Number of meetings to discuss services	3.60	1.21	4.28	.99
Progress in last six months	3.98	1.11	4.04	1.04
	Children with DD			
	Child (n = 11)		Parent (n = 72)	
	Mean	SD	Mean	SD
Overall satisfaction	4.82	.40	3.99	1.07
Providers' respect for family beliefs about mental illness	4.50	.71	4.18	1.02
Providers' understanding of family's culture	4.10	1.29	4.19	.94
Providers' ability to find services based on family strengths	4.60	.70	3.99	1.10
Level of involvement in planning	3.45	1.51	4.18	.92
Number of meetings to discuss services	4.18	1.17	4.10	1.04
Progress in last six months	4.27	.65	4.47	1.14

\* Scores range from (1) very dissatisfied to (5) very satisfied

Table 6. Family quality of life ratings (Feeling About Family Scale)

Scale	Children Ages 7-17				Children Ages birth - 6				All	
	MIC		DD		MIC		DD			
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Love	5.47	1.09	5.77	1.22	5.99	.92	6.05	.91	5.76	1.08
Status	4.92	1.27	5.27	1.34	5.25	1.22	5.52	.86	5.20	1.21
Service	4.83	1.22	4.97	1.23	5.12	1.17	5.15	.92	4.98	1.14
Information	4.80	1.13	5.00	1.12	5.11	1.27	5.10	1.05	4.97	1.10
Goods	5.32	.99	5.10	1.06	5.24	1.24	5.07	1.23	5.19	1.10
Money	4.13	1.54	4.14	1.66	4.15	1.43	4.21	1.53	4.16	1.53
Overall	5.32	1.14	5.46	1.50	5.76	.96	5.69	1.22	5.51	1.23

\* Scales range from (1) terrible to (7) delightful

Table 7. Family empowerment

Scale	Children Ages 7-17				Children Ages birth - 6				All	
	MIC		DD		MIC		DD			
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Family	4.18	.58	4.25	.50	4.50	.46	4.35	.58	4.28	.55
Service System	4.38	.58	4.49	.44	4.56	.44	4.46	.47	4.45	.50
Community/ Political	3.24	.89	3.56	.70	3.60	.95	3.42	.80	3.41	.84

\* Scales range from (1) not at all true to (5) very true